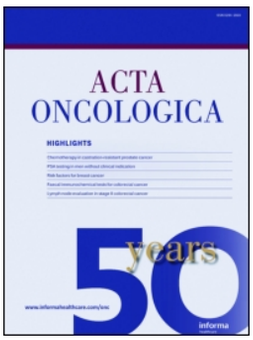

Acta Oncologica

ISSN: 0284-186X (Print) 1651-226X (Online) Journal homepage: https://www.tandfonline.com/loi/ionc20

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**To cite this article:** M. Jokela, M. K. Leinonen, N. Malila, M. Taskinen & L. M. Madanat-Harjuoja (2019): Completeness of pediatric cancer registration in the Finnish Cancer Registry, Acta Oncologica, DOI: 10.1080/0284186X.2019.1638522

**To link to this article:** https://doi.org/10.1080/0284186X.2019.1638522

ACTA ONCOLOGICA
https://doi.org/10.1080/0284186X.2019.1638522

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LETTER TO THE EDITOR



# Completeness of pediatric cancer registration in the Finnish Cancer Registry

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## Introduction

Population-based cancer registration plays a key role in malignant disease surveillance by providing data needed to calculate incidence, survival, cancer cluster investigations and prevalence trends. The Finnish Cancer Registry (FCR) maintains a national register of all cancer cases diagnosed in Finland and conducts epidemiological and statistical research on cancer [1].

The four main dimensions of cancer registry quality evaluation are validity, timeliness, comparability and completeness. Completeness is used to express the extent to which all incident cancers occurring in the population are included in the registry database [2]. Cancer registry data are utilized widely in cancer research and poor completeness of data introduces bias to incidence and survival estimates [3].

Rare diseases, such as childhood cancers, are sensitive to the effects of incomplete and/or inaccurate registration. Childhood cancer incidence has been reported to be higher in the Nordic countries compared to the rest of Europe [4]. This is thought to be explained by high completeness of the registers, as notification of new cancer cases is mandatory in all Nordic countries [5], and the Nordic cancer registries are reported to have close to 100% completeness for solid malignancies [6–10]. The survival rate of certain childhood cancer types (brain, lymphoma and acute lymphoblastic leukemia) in Finland was recently reported to be among the highest in the world [11].

The validity, comparability, timeliness and completeness of the FCR for the period of 2009–2013 have been previously described [6]. Completeness for all cancers was evaluated at 95% but the estimate for childhood cancers was, however, lower at 80%.

The aim of our study was to address possible data quality issues. The completeness of childhood cancer registration in the FCR in 2009–2013 was studied by tracing back potentially missed cases recognized by an independent data source. We explored completeness based on the cancer type and possible reasons underlying suboptimal completeness.

## Material and methods

The FCR compiles data on all incident cancers in Finland (since 1953). Health care providers have a statutory obligation to notify new cancer cases or strong cancer suspicions to the registry. Cancers reported to the FCR have been coded according to the ICD-O-3 [12] since the year 2007 and childhood cancer cases include an International Classification of Childhood Cancer (ICCC-3) [13] diagnosis code. The FCR has three independent information sources: clinical cancer notifications from hospitals, notifications from pathology laboratories and cause of death data received from Statistics Finland [1]. Due to mandatory reporting, cumulating information and active manual work in reviewing it, FCR data is of high quality [6].

The Care Register for Health Care (HILMO) contains data on all inpatient care episodes in health care centers and hospitals, and on all outpatient visits in public hospitals in Finland [14]. Completeness of HILMO has been estimated to be up to 95%. However, due to the administrative and cross-sectional nature of the data, the positive predictive value (proportion of cases confirmed as true positives) varies greatly, being lowest for rare diagnoses [15].

We used the independent case-ascertainment method [16] to assess completeness of the FCR by comparing FCR and HILMO data and verified the validity of the potentially missing cases by reviewing patient medical records (see below).

From the FCR, we extracted all childhood cancer cases (all malignant cases and all tumors of the central nervous system regardless of their malignancy) diagnosed at the age of 0–14 years in 2009–2013. We excluded basal cell carcinomas of the skin and classified neoplasms into non-solid tumors (hematological malignancies, ICD-O-3 morphology codes $\geq$9590) and solid tumors (all other malignancies) as previously described [6].

From HILMO, we identified all care episodes or visits in 2009–2013 with the following ICD-10 diagnoses: all 'C' codes excluding C44 basal cell carcinomas of the skin, D32-D33, D41-D43 and D45-D47. We chose the earliest date of hospitalization or outpatient visit with a relevant diagnosis under the age of 15 years. We then categorized the ICD-10-diagnoses as non-solid tumors (C81-C96 and D45-D47) and solid tumors (all the remaining) [6].

Solid tumors reported by HILMO were linked to the solid tumors found in the FCR using the unique personal identity code given to all residents of Finland. The same linkage was

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Supplemental data for this article can be accessed here.

performed for non-solid tumors. Cases in HILMO that could not be matched to cases in the FCR were considered potentially missed cases.

We requested patient information on all potentially missed cases from all university hospitals responsible for treating childhood cancer (Helsinki, Tampere, Turku, Kuopio and Oulu) using a structured enquiry form. Data on patients whose information could not be retrieved from university hospitals were inquired from patient file archives of smaller hospitals. Second, for all potentially missed cases, the notification and coding history at the FCR was manually reviewed.

Completeness estimates with 95% binomial confidence intervals were derived from the number of cases recorded in the FCR divided by the total number of cases (i.e., sum of cases recorded in the FCR and cases confirmed as missing from the FCR). We calculated completeness for all childhood cancer sites combined, for solid and non-solid tumors, for all 12 ICCC-3 main groups and for three age groups.

**Table 1.** Classification of the potentially missed cases after reviewing patient medical records.

| | |
|---|---|
| **Incorrect cancer diagnoses in HILMO** | **94** |
| Incorrect ICD-10 code reported to HILMO; correct diagnosis identified from the FCR | 25 |
| Non-registrable neoplasm or disease such as a cyst or infection | 23 |
| Benign tumor (outside the CNS)[a] | 13 |
| Benign blood disease | 9 |
| Typographical error | 9 |
| Malignancy not verified | 4 |
| Benign intracranial endocrine tumor[b] | 4 |
| Other or unknown reason | 7 |
| **Excluded cases** | **14** |
| Invalid personal identity code in the HILMO, patient could not be identified | 7 |
| Incorrect classification in the FCR database[c] | 5 |
| Not Finnish by nationality | 1 |
| Patient information not found in the hospital of supposed treatment or in any of the patient file archives | 1 |
| **Childhood cancer cases confirmed as missing from the FCR** | **49** |
| **Total** | **157** |

[a]Benign and borderline tumors of the CNS are registered in the FCR.
[b]Benign intracranial endocrine tumors i.e., tumors of pituitary gland, craniopharyngeal duct and pineal gland are not included in CNS tumors, and thus, are not registered in the FCR.
[c]Some ICD-O-3 codes had been incorrectly classified as solid or non-solid cancers in the FCR data and these cases had been incorrectly labeled as missing.

## Results

In the period 2009–2013, the FCR comprised a total of 741 incident childhood cancer cases. Of these, 441 were solid and 300 were non-solid cancers. A total of 1072 childhood cancer cases were retrieved from HILMO in 2009–2013 and 157 of these patients could not be matched to cases in the FCR.

Table 1 shows information on all 157 potentially missed cases after assessment of the patients' medical records. In all, 94 patients had an erroneous cancer diagnosis in HILMO. We confirmed 49 cases as true cancer patients that had not been notified to the FCR.

The highest proportions of incorrect cancer diagnoses in the group of potentially missed cases were present in ICCC-3 groups I (leukemia), II (lymphoma) and XI (malignant epithelial tumors); the proportions being 33 out of 43, 9 out of 9 and 11 out of 13 cases, respectively (Supplementary material).

Correcting the FCR data for 2009–2013 by adding the missing cases increased the total number of childhood cancer cases by 7% (from 741 to 790 cases).

### *Completeness of the FCR*

After confirmation of the 49 missing cases, completeness of the FCR was estimated at 94% (95% CI 92–95%) for all childhood cancer sites, 92% (95% CI 89–94%) for solid tumors and 97% (95% CI 94–98%) for non-solid tumors (Table 2).

Lymphomas, renal cancers and hepatic cancers showed 100% completeness. Lowest completeness was observed for central nervous system (CNS) tumors, retinoblastoma, bone cancers and other and unspecified malignant neoplasms (ICCC-3 group XII). Completeness of retinoblastoma was extremely low at only 55% (95% CI 36–72%), while all other cancers coherently showed completeness above 85% (Table 2).

We identified a slight, non-significant ($p$=.16) trend of increasing completeness with advancing patient age (Supplementary material).

**Table 2.** Completeness of childhood cancer (diagnostic age 0–14 years) registration in the Finnish Cancer Registry (FCR) and corrected number of childhood cancer cases, 2009–2013.

| ICCC-3 [13] main group | Cases in the FCR | Cases confirmed as missing from the FCR | Corrected number of cases | Completeness of the FCR (95% CI) |
|---|---|---|---|---|
| Total non-solid tumors | **300** | **10** | **310** | **96.8% (94.1, 98.4)** |
| I Leukemias, myeloproliferative diseases and myelodysplastic diseases | 243 | 10 | 253 | 95.7% (92.9, 98.1) |
| II Lymphomas and reticuloendothelial neoplasms | 57 | – | 57 | 100% (93.7, 100%) |
| Total solid tumors | **441** | **39** | **480** | **91.9% (89.1, 94.2)** |
| III CNS and miscellaneous intracranial and intraspinal neoplasms | 198 | 15 | 213 | 93.0% (88.7, 96.0) |
| IV Neuroblastoma and other peripheral nervous cell tumors | 40 | 1 | 41 | 97.6% (87.1, 99.9) |
| V Retinoblastoma | 18 | 15 | 33 | 54.5% (36.4, 71.9) |
| VI Renal tumors | 41 | – | 41 | 100% (91.4, 100%) |
| VII Hepatic tumors | 9 | – | 9 | 100% (66.4, 100%) |
| VIII Malignant bone tumors | 19 | 2 | 21 | 90.5% (69.6, 98.8) |
| IX Soft tissue and other extraosseous sarcomas | 45 | 2 | 47 | 95.9% (85.5, 99.5) |
| X Germ cell tumors, trophoblastic tumors, and neoplasm of gonads | 18 | 1 | 19 | 94.7% (74.0, 99.9) |
| XI Other malignant epithelial neoplasms and malignant melanomas | 47 | 2 | 49 | 95.9% (86.0, 99.5) |
| XII Other and unspecified malignant neoplasms | 6 | 1 | 7 | 85.7% (42.1, 99.6) |
| Total all tumors | **741** | **49** | **790** | **93.8% (91.9, 95.4)** |

## Discussion

We found the FCR to have high coverage (94%) of childhood cancers in 2009–2013, significantly higher than the previous estimate of 80% [6]. The completeness estimate for childhood cancers still remained slightly lower than the previous completeness estimate for all ages (95%).

In the independent case-ascertainment method, registry data are compared to data from another, independently compiled registry source [16]. In administrative registries such as HILMO, however, erroneous diagnoses are common [15,17] and administrative claims provide only a robust tool to determine the extent of missing registry data [18].

When using unvalidated hospital discharge data for cancer research and incidence statistics, the number of false positive cancer diagnoses warrant caution. Leukemias, lymphomas and epithelial neoplasms had a high proportion of false positive cancer diagnoses in HILMO; benign abnormalities of blood, benign lymphadenopathy and benign skin tumors are common clinical findings occasionally incorrectly registered to HILMO with a malignant ICD-10 code. It has previously been reported that more than half of myelodysplastic syndrome or myeloproliferative neoplasm cases retrieved from HILMO were missing from the FCR [19]. We, however, observed that among childhood patients, 75% of the myelodysplastic syndrome or myeloproliferative neoplasm cases potentially missing from the FCR were, in fact, false positive cancer diagnoses in HILMO.

### *Completeness*

Our evaluation supports high completeness of childhood cancer registration in the FCR at 94% for all sites, with 92% for solid cancers and 97% for non-solid cancers. Completeness was lowest for CNS tumors, retinoblastoma, bone cancers and unspecified cancers. Completeness was highest for lymphomas, renal cancers and hepatic cancers. However, results concerning bone, hepatic and unspecified cancers were based on small numbers.

The quality of childhood cancer registration has not been widely studied and published reports have focused on pediatric cancer registries [20–25]. Pediatric cancer registries often operate closely with pediatric oncology clinics and their data sources may differ from those of population-based national cancer registries such as the FCR [26]. Completeness of the Swiss Childhood Cancer Registry has been estimated at >95% and lowest completeness was reported in tumors of digestive organs, endocrine glands and the brain [21]. In Britain, completeness of childhood cancer registration in general British cancer registries has been estimated at 92–96%. Registration of retinoblastoma was poor in the general registries but complete in the National Registry of Childhood Tumors [22]. Completeness of childhood leukemia registration in the Dutch Leukemia Study Group and in the Dutch Cancer Registry has been estimated at 96.9% and 95.5%, respectively [23].

We could indicate missing cancer notifications in tumors lacking histological verification such as cancers of the eye and tumors of the CNS. Retinoblastoma patients comprised over one-third of the cases missing from the FCR. When diagnosing retinoblastoma, biopsies are contraindicated [27] and eye enucleation as treatment (allowing for a pathological sample) is rarely performed [28]. Both childhood and adulthood CNS tumor registration in the FCR is incomplete [6]. The childhood CNS tumors confirmed as missing from the FCR were mainly nonmalignant or had neither been biopsied nor surgically removed (i.e., no pathological notification was available).

For cases missing from the FCR (other than retinoblastomas and CNS tumors), common traits were long diagnostic processes and rare diagnoses. A cancer notification should always be made to the FCR when a conclusive diagnosis is reached. We also identified three individuals diagnosed abroad who had not been notified to the FCR despite returning to Finland.

Previously, completeness of childhood cancer registration in the FCR was estimated at 80%, with 179 persons diagnosed with childhood cancer registered to HILMO but not to the FCR, compared to the 157 cases potentially missing in this study [6]. After reviewing the linkage process, we found that 22 patients had been misclassified as adults in the previous report due to uncertainty related to the time of diagnosis.

### *Moving forward*

As of 2020, the FCR will no longer accept clinical cancer notifications on paper. The FCR now provides a new web-based notification system for cancer reporting. The required data fields have been minimized in order to motivate reporting.

The FCR has contacted the units with systematic low reporting and they have internally discussed possible underlying reasons.

Registration of cancers with no pathological samples, and therefore, no notifications from pathology laboratories relies on clinical cancer notifications. Oncologic units are well informed on when to send cancer notifications to the FCR; special attention will be targeted toward non-oncologic units treating these neoplasms such as ophthalmological and neurosurgical units.

Our study led to the observation that intraocular cancer reporting in the main treating unit had failed due to technical errors and the notification procedure has been corrected. Regarding CNS tumors, we have reformulated the guidance and sampling processes in the pathology laboratories to include all benign neoplasms of the CNS.

Based on the findings of our study, the FCR will implement a completeness evaluation process using HILMO for identifying potentially missing cases in the registry routine.

## Conclusion

The FCR yields high-quality data for childhood cancer. The completeness of childhood cancer registration was estimated at 94%. Compared to cancer in adulthood, completeness of childhood cancer registration lags behind, calling for

attention to quality control measures in this subgroup of rare tumors. Disseminating results on data quality is needed to increase awareness of the need for clinical cancer notifications.

## Acknowledgments

We gratefully acknowledge all Finnish hospitals for their collaboration in collecting and reviewing patient data.

## Disclosure statement

The authors report no conflicts of interest.

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